The organization of generalist medical care for people with intellectual disabilities in the Netherlands

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Summary

People with intellectual and developmental disabilities (IDD) face health disadvantages and a lower life expectancy. Adequate and easily accessible primary care plays a key role in improving the health of this vulnerable group. According to the WHO, primary care concerns "the first level of contact of individuals […] with the national health system bringing healthcare as close as possible to where people live and work" (1). This article describes the current organization of the primary medical care for people with IDD, the role of the general practitioner (GP), and the role of the specialized ID physician.

Introduction

An average general practice in the Netherlands provides care for about ten people with IDD (2). This is probably an underestimation because having an IDD is often not properly registered. Additionally, several policy changes have taken place in healthcare since the study took place in 2007. As a result of these policy changes, people with IDD became more dependent on the GP for primary care. Also, the use of care by people with IDD continues to increase. This also applies to primary care, both during the day and at night, and on weekends. The continuing increase in healthcare use can also be attributed to the increasing life expectancy of this group of people and the increased complexity of society.

Organization of medical care for people with IDD in the Netherlands

As having an IDD is not registered by default, no exact numbers of people with IDD are known. The Netherlands Institute for Social Research estimates the number of people with IDD at 142,000. The group of people with borderline intellectual functioning (IQ 70-85) is estimated to be at 2.2 million (3). A recent study by Cuypers et al. (2021) based on the Dutch population register and databases from public services accessible with an ID diagnosis identified 187,149 adults with IDD in a population of almost 12.7 million Dutch adults (4).

In the Netherlands, healthcare for people with IDD is financed in various ways. Figure 1 provides a global overview of the current model of healthcare for people with IDD in the Netherlands. In 2015, the General Act on Exceptional Medical Expenses (AWBZ) was split up into the Social Support Act (Wmo) and the Long-term Care Act (Wlz). The Care Assessment Center (CIZ) determines whether a person qualifies for care under the Wlz or the Wmo. People with IDD who fall under the Wmo live in the community, either with family or independently, with or without ambulatory guidance. These people make use of facilities in the community, including the GP. People with IDD who fall under the Wlz receive healthcare through care

organizations where ID physicians or GPs work. The Netherlands has approximately 120 care organizations for people with IDD (5).

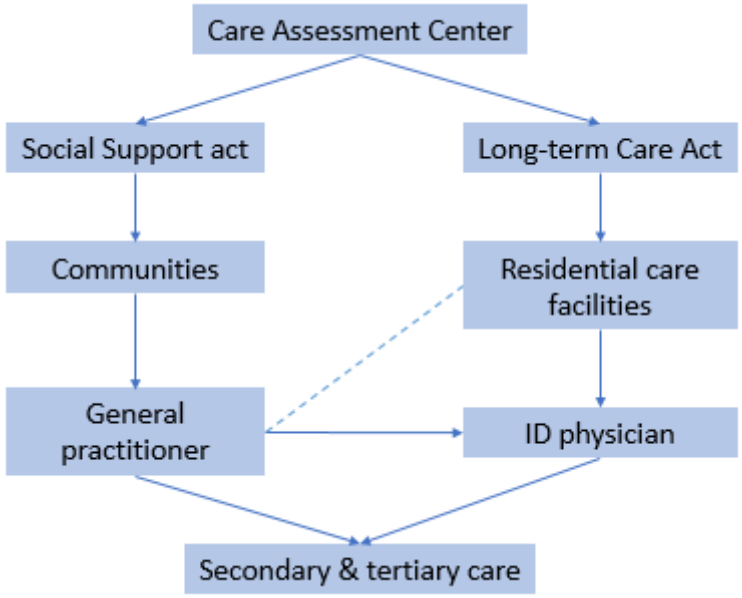

Figure 1: The organization of the medical care for people with IDD in the Netherlands

As of January 2020, the Care Insurance Act (Zvw) finances general medical care for specific vulnerable target groups who live at home, including the care provided by an ID physician. This concerns all medical care, diagnostics, and drawing up a treatment plan, regardless of the age of the patient (6). In contrast to a visit to the GP or general practice, there is a deductible for visits to the ID physician, the specialist in elderly medicine, and the hospital.

People with IDD and the GP

People with IDD visit the GP on average 1.7 times more compared to the general population (2). Research in 2014 showed that 95% of GPs have patients with a mild IDD in their practice, 68% have patients with a moderate IDD, and 26% have patients with a severe IDD in their practice (7). Of all GPs included in this study, 58% foresaw problems if the number of people with IDD in their practice increased and 64% already experienced problems with the care for this group. This mainly concerned a lack of knowledge about psychological and behavioral problems and specific syndromes that occur more often in people with IDD.

The role of the ID physician

In 2000, the medical specialty of an ID physician was officially recognized by the Minister of Health of that time in the Netherlands. Specialized ID physicians are trained during a three-year course in all the aspects of medical care for people with IDD. In the Netherlands, about 230 ID physicians are registered. They work in care organizations, outpatient clinics, or specialized day centers. The Netherlands counts about 80 outpatient ID clinics. These clinics are visited by

people with IDD for medical consultation or treatment. Both patients and referrers can contact the ID physician working in an outpatient practice. The GP is one of the most important referrers to the ID physician (10). Often, outpatient clinics are linked to a healthcare organization, but some outpatient clinics are linked to a hospital or care center.

ID physicians can be consulted by referral or by telephone consultation. Often, they are consulted by patients with co-morbidities or by patients for who it is not clear whether they experience a somatic or behavioral problem. In general, the more complicated the care profile of people with IDD, the more the ID physician is involved (9).

The following subjects are designated as areas of focus for the ID physician (11):

- Specific medical monitoring (health watch) for syndromes (Down syndrome, Prader-Willi, etc.);
- Etiological research into the cause of the IDD;
- Epilepsy;
- Spasticity, musculoskeletal problems;
- Gastrointestinal issues such as PEG tube decision making, constipation, and reflux;
- Swallowing disorders and recurrent respiratory infections;
- Sensory disturbances (high prevalence);
- Behavioral problems and psychiatry;
- Sleep disturbances;
- Sexuality, contraception, and desire to have children;
- Life stage problems such as questions about increasing independence, living and working in adolescence;
- End-of-life care, palliative care;
- Legal capacity and legal representation;
- Legislation and regulations (BOPZ, Wgbo, BIG, Wlz);
- Support and second opinion in complex decision-making regarding treatment policy, considering medical, ethical, and legal aspects.

People with IDD and after-hours primary care (evening, night, and weekend)

In the Netherlands, after-hours primary care for the general population is organized via GP cooperatives and is known for being accessible, efficient, safe, and well-organized. Little is known about this care for people with IDD. Recent research by Radboudumc has shown that the GP is involved in 77% of the care organizations for people with IDD, usually via the GP cooperatives, but often not for all homes and residents of these organizations (12). In 43% of the care organizations, an ID physician was also involved in out-of-hours primary care. The ID physician can have different roles in this care: as a gatekeeper, as a care provider, or as a consultant for the GP (5).

Optimal generalist medical care for people with IDD requires collaboration

People with IDD experience significant health inequalities and have a lower life expectancy compared to the general population. They have a greater chance at undetected and untreated complaints and are more likely to have to deal with multimorbidity and polypharmacy (2, 13,

14). Good and easily accessible primary care plays a key role in improving health for this vulnerable group.

Both the GP and the ID physician provide medical care for people with IDD in the Netherlands. Both healthcare professionals provide general medical care as well as target-group-specific medical care. The general medical care provided by the ID physician is less broad than that of the GP and the target-group-specific medical care provided by the GP is less broad than that of the ID physician (Figure 2). Both medical care providers are thus complementary to each other and there is some overlap in the care they provide (8).

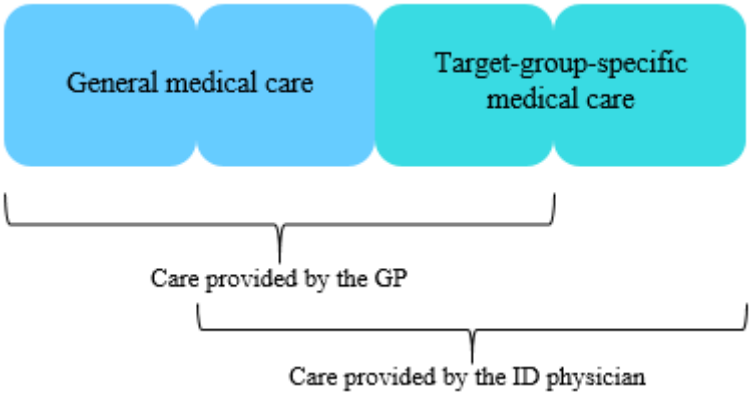

Figure 2: The relation between medical care provided by the GP and the ID physician

Caring for a patient with ID often means deviating from routines and therefore brings an extra burden. The ID physician has expertise in the field of specific health and communication problems of people with IDD but is not trained as a GP. Optimal generalist medical care for people with IDD requires collaboration between the GP and ID physician. Changes in the healthcare landscape mean that the interpretation of this collaboration deserves attention.

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